

# Information needs and information sources of individuals living with spinal cord injury

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## Abstract

*Aims and objectives:* Access to health information is important for the well-being of people living in the community after spinal cord injury (SCI). In order to design appropriate information interventions, it is critical first to understand the information sources typically used. The goal of this study therefore is to identify the information-seeking practices of this group.

*Sample and methods:* A sample of 207 individuals living in the community following traumatic spinal cord injury were surveyed regarding their ongoing information needs and practices for seeking information.

*Results:* The results reveal that respondents have unmet information needs, despite the fact that they typically access information through a variety of channels. SCI specialists are the most commonly used source, although they are viewed as relatively inaccessible. By contrast, the Internet (used by a relatively high proportion of respondents) is viewed as comparatively accessible, although there are some concerns about the quality of information found there.

*Conclusions:* These survey results point to the need for an information source that is accessible and delivers high quality information. Although respondents use a variety of information sources, none meets this ideal profile. Information professionals should consider this gap in the design of information interventions.

## Introduction

Self-directed care is an important aspect of health, particularly for those living with unresolved health conditions such as chronic illness, disability, or progressive disease.<sup>1</sup> For these individuals, the prevention, identification, and management of complications associated with the primary condition become part of everyday life. Information that supports an understanding of the condition and the ability to identify effective care strategies is obviously critical to these individuals.<sup>2,3</sup>

Healthcare providers offer comprehensive education during initial contact with the healthcare system,<sup>4</sup> but information needs change over time, and as a result information seeking is a lifelong effort for individuals living with chronic conditions. One important challenge for health educators and information professionals is to deliver this information when and where it is needed. Once an individual is discharged from acute care, there is no obvious route for information delivery. One approach is to deliver information through familiar and trustworthy sources.<sup>5-7</sup> In order to use these sources, they must first be identified. The present investigation examines this issue with respect to one population: individuals living in the community following traumatic spinal cord injury (SCI).

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## Background

### Health information sources

Within the literature, information sources are often characterized as falling into two main groups:

- interpersonal sources for health information, e.g. healthcare providers (GPs, specialists) and peers living with the condition;
- mass media sources, e.g. books, magazines and television.

Mass media sources tend to provide general information relevant to a broad population without being specific to any one person or small subgroup, while interpersonal sources are better able to address individual information needs.<sup>8</sup> In general, people use a variety of both types of sources for health information.<sup>3,9</sup>

Healthcare providers, especially specialists, are the interpersonal health information sources most widely used by those living with chronic conditions<sup>10–12</sup> and are often viewed as the most easily accessible and trustworthy.<sup>10–13</sup> Other interpersonal information sources such as friends or family are also important, especially at or near the time of diagnosis.<sup>14</sup> Many of the interactions with interpersonal information sources conform to the two-step flow model<sup>15</sup> in which information is accessed through an intermediary.<sup>4,16</sup> Peers living with the same condition are another important source, unique because they can offer insight based on their own experience.<sup>3,4</sup>

Mass media sources and print material, including medical books, pamphlets, newspapers, and periodicals, are also important sources, cited as providing health information related to chronic or unresolved illness<sup>4,17</sup> and other media sources including television and radio may be widely used in some circumstances.<sup>4</sup>

The Internet is a relatively new source of health information.<sup>11</sup> It has been variously characterized as an interpersonal communication medium, a mass communication medium<sup>18</sup> and a hybrid medium that combines characteristics of both depending on the application that is being used.<sup>19</sup> Use of this source varies widely among those with chronic or unresolved health conditions, from fewer than 10% of respondents in some investigations<sup>4,11,16</sup> to well over 25% in others.<sup>20–22</sup> There is reason to

believe, however, that use of the Internet will increase as more people gain access and become familiar with it.<sup>23</sup>

### The context for spinal cord injury: rehabilitation, secondary complications and information use

Health information is particularly important for those living in the community following spinal cord injury (SCI). Typically, individuals sustaining an SCI undergo a period of acute care during which their condition is stabilized and their immediate medical need addressed. After stabilization, patients participate in intensive inpatient rehabilitation and education, during which they are provided with extensive information regarding the management of their condition, including details regarding the prevention, identification, and treatment of SCI-related complications.<sup>24,25</sup> The vast majority of patients (i.e. ~95%) are discharged to the community at the end of this period.<sup>26</sup> Although it is usual to provide an annual evaluation for SCI patients discharged to the community, many individuals fail to attend, and contact with specialists and healthcare professionals in general tends to decline with increased time since injury.<sup>27,28</sup>

Individuals living with SCI face a variety of secondary health complications related directly or indirectly to their injury.<sup>29–31</sup> With appropriate self care, the incidence and/or severity of many of these complications can be reduced.<sup>32,33</sup> Although complications can occur any time following injury, their incidence, and thus the need for information about prevention and treatment, tends to increase with time.<sup>29,34</sup>

Information about how to prevent, recognize, and treat complications associated with SCI is an integral component of inpatient spinal cord rehabilitation programmes.<sup>24,35</sup> For a variety of reasons, however, the information provided is insufficient to meet ongoing information needs.<sup>36</sup> As a result, individuals living with SCI have an ongoing need for health-related information regarding their injury and the prevention, identification, and management of associated complications.

## Objectives of the study

In order to deliver health information effectively to individuals living in the community following

SCI, it is critical to understand how and where they seek health information. Literature examining the information-seeking patterns of other populations provides some insight. Preferred information sources, however, differ across groups<sup>10,37</sup> and thus the results from one population cannot simply be generalized to another. The goal of this study is to provide a description of the information-seeking practices of those living with SCI. Specifically, to address:

- perceived information need;
- use of information sources;
- demographic factors that relate to information source selection.

The results presented here represent part of a larger survey focused on the experiences of individuals living in the community following traumatic SCI. Questions pertaining to information needs and information seeking are analysed here.

## Methods

### Selection of participants

Prospective participants were randomly selected from three different sources:

- 1 a large Southwestern Ontario regional SCI rehabilitation outpatient programme;
- 2 a provincial paraplegic consumer association;
- 3 a national SCI research organization.

Prior to any contact with participants, approval for the study was received from the University of Western Ontario Research Ethics Board. In addition, separate approval was sought from the provincial paraplegic association and the national SCI research organization. These three sources provided a comprehensive coverage of individuals living in the community in Ontario following traumatic SCI. For example, the first group was restricted to individuals in Southwestern Ontario, while the other two groups had full provincial coverage. The different mandates of the groups also helped to ensure broad coverage: the first group represented individuals in active outpatient rehabilitation, while the other two consumer groups included individuals who were not necessarily participating in active rehabilitation.

All eligible participants were resident in Ontario, Canada and had experienced a SCI as a result of a

traumatic injury when they were 18 years of age or older. One thousand individuals were invited to participate in the survey: this group represented a stratified random sample drawn in approximately equal numbers from the three sources (334 from the SCI rehabilitation programme, 333 from the consumer association, and 333 from the research organization).

### Data collection

Questionnaires were posted to participants inviting them to complete the survey and return it in the enclosed stamped addressed envelope: a small incentive (a Canadian \$1.00 coupon from a national fast food chain) was also given. In addition, two alternative forms of administration were offered: by telephone or over the Internet. To encourage participation, participants selected from the first two sources were contacted by telephone no sooner than 2 weeks after the initial mailing and invited to complete the survey by telephone. No follow-up was possible for participants recruited from the third source.

The survey included questions on a variety of topics including demographic characteristics, health status, injury-related complications, use of assistive devices, and use of information sources. The results reported here reflect that portion of the survey that addressed information needs and information sources.

### Response rate

A total of 81 respondents were lost to the sample because they did not meet inclusion criteria ( $n = 8$ ), had incorrect contact information ( $n = 59$ ), or were deceased ( $n = 14$ ). Thus, the number of potential respondents was 919. Of these, 207 (22.5%) completed the surveys. The vast majority of responses were via post ( $n = 186$ ) as compared with the Internet ( $n = 18$ ) or phone ( $n = 3$ ). Slightly under half the respondents in the final sample (43.4%) were recruited from the rehabilitation programme, 31.4% from the consumer association, and 25.1% from the research organization.

The low response rate limits the generalizability of survey conclusions.<sup>38</sup> Nonetheless, we believe

that the results are valuable. Little is known about information seeking by individuals living with SCI in the community, and in order to improve their health care it is important to understand ways in which information is sought. This study represents the first to examine the use of information sources by people with SCI, and as a result will provide important initial insights into behaviour. Furthermore, the sample appears similar to the general population of individuals living with SCI. These similarities exist for gender<sup>39,40</sup> age of injury<sup>39,41</sup> level of injury<sup>39</sup> and aetiology.<sup>39,41</sup>

### Characteristics of respondents

Most of the 207 respondents were male (68.5%). The average age of respondents was 49.4 (SD 14.3, median 47.5) and the average age at the time of injury was 37.0 years (SD 16.4, median 33). Most respondents (94.7%) reported their current educational level, and of these 41.8% had completed some post-secondary school education (college or university), 39.8% had completed high school but not any post-secondary school education, and 18.4% had not completed their high school diploma.

SCI often, although not always, results in significant mobility impairment. Within this group of community-dwelling respondents, only 25% reported walking as a primary means of mobility (15.2% required an aid for walking, 9.8% could walk without an aid). Almost three-quarters (74%) of the respondents required either manual or power wheelchairs for mobility (51.8% manual wheelchairs, 22% power wheelchairs; the remaining 1.2% report other primary means of mobility).

People with SCI receive inpatient rehabilitation at the time of their injury, but this represents, for some individuals, the only opportunity for formal

education regarding complications associated with SCI. Within this group of respondents, the minimum reported length of rehabilitation was 2 days, and the maximum reported length was 45 months. On average, respondents reported 7.1 months of rehabilitation (SD 5.8, median 6.0), and the average amount of time that had passed since their injury and rehabilitation was 12.4 years (SD 9.2, median 10.6).

## Results

### Information needs

Respondents were asked to rate the importance of access to information in managing their health and health care on a 5-point scale ranging from 'never important' to 'always important', and to rate the availability of information on a 5-point scale ranging from 'never available' to 'always available'. Of those responding to these questions, the large majority (88%) indicated that information is 'usually' or 'always' important to their health (see Table 1). Most respondents indicated that information was 'usually' or 'always' available when they need it (75%), and this proportion was slightly higher (78%) when considering only those who indicate information is 'usually' or 'always' important. Nonetheless, almost one-quarter (22%) of those who felt information was important to managing their health identified some difficulty accessing the information they require.

Respondents were asked to indicate the SCI-related complications they were experiencing at the time of the survey by choosing from a list of 29 common complications and one open category. Using the same list, they also indicated complications they had experienced at any time. On average, each respondent had experienced 11.7 of

	Importance		Availability	
	<i>n</i> (187)	%	<i>n</i> (180)	%
Never (important or available)	2	1.1	7	3.9
Rarely (important or available)	7	3.7	23	12.8
Undecided	13	7.0	15	8.3
Usually (important or available)	53	28.3	59	32.8
Always (important or available)	112	59.9	76	42.2

**Table 1** Perceived importance and availability of information as a factor that might affect health

the 29 complications (SD 4.38, median 12), and was currently experiencing 7.2 of the 29 complications (SD 3.66, median 7). Only one respondent indicated that they had never experienced any of the complications, and only two indicated they were not currently experiencing complications. The most commonly experienced complications were pain (87% ever, 68% currently), spasms (80.7% ever, 72.9% currently), shoulder pain (74.4% ever, 58.9% currently), and urinary tract infections (80.2% ever, 28% currently). A detailed discussion of the prevalence of various complications is beyond the scope of this paper, but these data clearly indicate that the vast majority of survey respondents experience SCI-related complications. The relatively high incidence of complications provides additional evidence of information related to the prevention and management.

### Information sources

Where do individuals with spinal cord injury go for health-related information? In an attempt to answer this question, respondents were asked to indicate the sources they use to obtain information related to their spinal cord injury by choosing

from a list that included both interpersonal sources (GPs, specialists in SCI; other health-care providers; individuals with SCI, and the Internet in the form of e-mail or chat groups) and mass media sources (magazines, journals, or newsletters; books; and television or video; note that the Internet is treated separately as a hybrid information source).

Most people (88%) reported using multiple sources (see Table 2), with a median of four different information sources per individual (minimum 0, maximum 10). Interpersonal information sources are heavily used within this population: 92.8% report using at least one interpersonal information source. Of these, SCI specialists were used by the largest proportion of respondents (78.7%), followed by general physicians (74.9%), other healthcare professionals (58%), and others with SCI (57%). Approximately one quarter cite SCI specialists as the most frequently used source (27.6%), and approximately one quarter cite general physicians (23.9%). These results clearly demonstrate that those living in the community with spinal cord injury use interpersonal information sources, and particularly healthcare professionals, when they are seeking health-related information.

**Table 2** Information sources used by respondents

Information source	Used at all		Used most frequently	
	<i>n</i> (207)	%	<i>n</i> (160)	% of those who use the source
<b>Interpersonal sources</b>				
SCI specialist	163	78.7	45	27.6
General physician	155	74.9	37	23.9
Other health-care professional	120	58.0	22	18.3
Others with SCI	118	57.0	19	16.1
E-mail or chat groups	14	6.8	0	0
<b>Mass media sources</b>				
Magazines, journals or newsletters	118	57.0	15	12.7
Books	57	27.5	0	0
Television/video	56	27.1	1	1.7
Other	11	5.3	3	27.3
<b>Hybrid sources</b>				
Internet web pages	72	34.8	18	25
<b>Groupings</b>				
Any health-care professional	189	91.3	104	55.0
Any interpersonal source	192	92.8	123	64.1
Any mass media source	137	62.2	19	13.9



**Table 3** Mean ratings of information quality

Information source	Number of responses	Speed	Accessibility	Accuracy	Specificity	Currency
Physician, specialist* <sup>1</sup>	135	2.37 <sup>b</sup>	2.26 <sup>b</sup>	2.70 <sup>a</sup>	2.65 <sup>a</sup>	2.73 <sup>a</sup>
Physician, GP	133	2.27	2.35	2.27	2.22	2.21
Other health-care professional	100	2.31	2.29	2.38	2.34	2.33
Others with SCI	102	2.35	2.14	2.27	2.25	2.27
Magazines, journals or newsletters* <sup>2</sup>	89	2.15 <sup>b</sup>	2.12 <sup>b</sup>	2.34 <sup>ab</sup>	2.15 <sup>b</sup>	2.45 <sup>a</sup>
Internet web pages* <sup>3</sup>	63	2.81 <sup>a</sup>	2.76 <sup>a</sup>	2.38 <sup>b</sup>	2.25 <sup>b</sup>	2.46 <sup>b</sup>
Books	41	2.17	2.20	2.24	2.02	2.17
Television/video	47	2.02	1.89	2.21	1.90	2.23
E-mail or chat groups	11	2.72	2.72	2.45	2.36	2.55

\*Indicates significant differences among quality ratings—ratings with different superscript letters are significantly different from one another: <sup>1</sup> $F_{1,134} = 28.35$ ,  $P < 0.001$ ; <sup>2</sup> $F_{1,88} = 9.776$ ,  $P < 0.01$ ; <sup>3</sup> $F_{1,62} = 23.436$ ,  $P < 0.001$ .

The widespread use of interpersonal information sources is in striking contrast to the results for mass media sources. Less than two-thirds of respondents (62.2%) use one or more mass media sources. Although a relatively high proportion (57%) report using magazines, journals, or newsletters as information sources, usage rates for other mass media sources are much lower. Furthermore, it appears that mass media sources tend to be used as adjunct rather than primary information sources, as a much smaller proportion (less than 10%) who use the mass media sources report that these are their most frequently used sources.

Approximately one-third (34.8%) of respondents (49.7% of those with access to the Internet) reported using the Internet as an information source. Those who use the Internet as a source tend to consult it frequently: 25% of those who use the Internet identify it as their most frequently used information source.

For the sources used, respondents were asked to rate five measures of quality, two of which pertain to source availability (accessibility and speed), and two of which pertain to quality of the information provided (accuracy, currency, and specificity), on a scale of 1 (poor) to 3 (good) (see Table 3). One important question is whether ratings of these qualities differed within information sources: that is, is a source strong or weak with respect to all qualities, or are sources better in some areas and weaker in others? Repeated measures analyses of variance followed by post-hoc test of means<sup>42</sup> were used to investigate this question. Only three

sources showed differences across the five qualities: SCI specialists, the Internet, and periodicals. For SCI specialists, accessibility and speed were rated lower than accuracy, currency, and specificity (no differences were found within these two groups). In contrast, the Internet was rated higher for speed and accessibility than for accuracy, currency and specificity (with no differences within these two groups). The pattern of results for periodicals was more difficult to interpret, but in general information from these sources was viewed as relatively up to date (currency rated higher than accessibility, speed, and specificity).

SCI specialists are arguably the most reliable source of medical information related to SCI, but there is some suggestion that access to this information source decreases with time since injury. Our data are consistent with this observation. Among this sample of respondents, there is a significant relationship between use of an SCI specialist and time since injury (SCI specialists are used as an information source by 89.9% of those injured within the last 6.5 years, 76.8% of those injured 6.5–14.5 years ago, and 69.6% of those injured more than 14.5 years ago,  $\chi^2_{(2)} = 9.34$ ,  $P = 0.009$ ). Use of other information sources is unrelated to time since injury.

## Discussion

People living in the community with SCI clearly have a need for information. Most respondents identified information as an important factor in

the ongoing management of their SCI and related complications. The majority indicated that they have adequate access to the information, over one-fifth feel that they have difficulty accessing information. Furthermore, consistent with previous research,<sup>30,31,43</sup> there was a high incidence of complications among this group, including many complications that are largely preventable given appropriate self-care measures (e.g. pressure sores, urinary tract infections, shoulder pain as a result of repetitive movement). These results suggest that these individuals have ongoing health-related information needs.

Interpersonal information sources were used by almost all respondents. Most respondents used more than one source for health-related information, with the vast majority of respondents indicating that they used at least one healthcare professional (SCI specialist, general physician, or other healthcare practitioner). Similar findings have been reported in other studies.<sup>10,11,11–13</sup> Others living with SCI were also a commonly used information source. The only mass media source that was used by a large proportion of respondents was periodicals (magazines, journals, or newsletters).

Not surprisingly, SCI specialists were consulted by the largest majority of respondents and were most likely to be indicated as the most frequently used source. This widespread use of SCI specialists occurred despite the relatively low ratings for their availability and decreasing use with increasing time since injury (this last point is consistent with previous research<sup>27</sup>).

The Internet was viewed as a highly accessible source, used by one-third of all respondents, and one half of those with Internet access. On the whole, however, information from this source was not viewed as being as high quality as that from SCI specialists. Approximately two-thirds of respondents indicated they have access to computers and specifically to the Internet, a level that has been found in other studies of community-dwelling individuals with SCI.<sup>44</sup> Where the Internet was used it was quite likely to be the most frequently used source.

It is notable that the quality profiles of SCI specialists and the Internet are mirror images: SCI specialists are viewed as relatively inaccessible, although providing high quality information,

while the Internet has the opposite character. This distinction between sources that provide the best information and those that are most accessible is consistent with previous research.<sup>45</sup>

## Conclusion

People living with SCI in the community have ongoing health-related information needs. These needs are exacerbated by the changing nature of the information required by someone encountering a life-changing traumatic event such as an SCI which also results in the potential for various secondary long-term health complications. The results of this survey demonstrate that healthcare providers—especially SCI specialists—are important sources of health information for people with SCI living in the community. From the perspective of information consumers, SCI specialists provide high quality information. At the same time, however, specialists are only moderately accessible to community-living individuals, and accessibility of this resource decreases with time since injury. In contrast, the Internet is viewed as an available source of health-related information, although the information provided by this source is perceived as being of lower quality than information provided by SCI specialists. The results of this survey suggest that, from the perspective of information consumers, no single source meets the long-term need for accessible, high quality information. Information professionals should take this feedback into account when designing information interventions for these and other individuals living with chronic health conditions, and attempt to provide access to the specialized expertise and information required by these individuals.

## Acknowledgements

The authors wish to thank Sheri Hartley and the rest of the research team for their invaluable assistance. In addition, without the participation of the Canadian Paraplegic Association Ontario and the Canadian Spinal Research Organization this project would not be possible. The authors also gratefully acknowledge the support of the Ontario Neurotrauma Foundation. The results

and conclusions are those of the authors and no official endorsement from the Government of Ontario is intended or inferred.

### Key Messages

#### Implications for Practice

- Individuals living in the community after spinal cord injury have an ongoing need for accurate and up-to-date information related to their condition.
- These individuals are active information seekers who use a variety of information sources.
- Available sources of this information are insufficient, either because they are inaccessible or because the information they provide is not accurate, specific, and up to date.

#### Implications for Policy

- Individuals living with complex chronic conditions require access to appropriate health information;
- Current information sources do not meet the dual needs of accessibility and information quality;
- Information interventions should focus on making expert information accessible to those who do not have ongoing intense contact with the health-care system.

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Received 8 December 2005; Accepted 23 August 2006